COMMENTS ON 1115 AND 1915c WAIVERS

One big concern is mixing the IDD concepts (one waiver) in with medical concepts (eight waivers). The purpose, focus and spirit of a Medicaid IDD program are different from medical systems. The difference cannot be stressed to strongly.

General concerns regarding mixing in Medicaid IDD wavier.

See 435.1009 for eligibility to the Medicaid IDD program, both ICFIID and related waiver. There are NO medical conditions mentioned or required. Cancer, Lupus, Broken bones at any age does not meet eligibility requirements for Medicaid IDD programs. Medical conditions are unrelated conditions for eligibility determination.

Mental illness is specifically identified as an Unrelated Condition under 435.1009. So having a mental illness as an adult or a child is not considered, regardless of how severe, when determining eligibility to an IDD program.

Eligibility for Medicaid IDD is stressed because Illinois has persistently ignored Medicaid regulations. OBRA87 and OBRA93 that people with IDD must be placed in the IDD programs for FFP (OBRA87) and the Preadmission system as proper placement (OBRA93). There is also Bogard vs. Wright.

Eligibility is an Intellectual Disability, IQ under 70 or a Related Condition e.g., Autism or cerebral palsy AND deficits of at least three out six life areas caused by the related condition.

1115 – How will the Single Point of Entry system meet these assurances for Medicaid IDD programs?

See 483.440 Active Treatment

The purpose of the programs is participation in everyday life, person centered systems for individual participation in life planning and now, expressly living one's life in a neighborhood surrounded by others who do NOT have a disability. No more segregation of people with IDD from "Normal" people.

441.302(d) State Assurance of Choice with the Waiver

The state must assure that a person (or guardian) likely to be to require ICFIID (also those for NF/SNF) be informed of feasible alternative under the waiver and given the choice of institutional or home and community based services.

This state assurance has been in place since March 1985. The IDD system in Illinois did not implement the assurance or at least recognize its existence until the Ligas class action suit. That's 25 years to meet the requirement.

1115 preadmission and the opportunity of choice for community placement by people in institutions (fits into Rebalancing) must be explicit and overseen closely.

IDD Waiver Issues:

1. DSP wages have increased $0.79 (79 cents) in 13 years ($9.92 to $10.71 in the CILA Reimbursement System). See 2002 CILA Manual for initial DSP wage. That's rounds out to an 8% increase. Minimum Wage over the same period showed a 60% increase ($5.15 to $8.25). DSPs have taken a big loss over the years. If DSP wages had increased relative to Minimum Wage, the wage would be slightly more than $15/hr. It's very difficult finding staff. Applicants are either very dedicated to human services or very unemployable for good reason.

2. The IDD waiver system is based on and is a smaller scale institutional system. CILA requirements reflect ICFIID requirements. It's time to move into the community – be a neighbor- rather than a group home in R2 zoning areas.

3. The CILA-Day Program split makes no programmatic sense. The Day program is 1100 hours, which is less than a 12 month year. Why? Where are people in the CILA supposed to go and do when the 1100 hours are up? What's the concept here that leads to a better life? The Day Program system should go to 240 days of service and revisit the number of hours per day funded. The ICFDD system funds 8 hours per day for 240 days. Such a model could be modified to include work/employment support programs thereby increasing the number of options on how to spend funds under one system rather than have multiple (independent) systems. All could be covered under the waiver.

4. The Day program funding does not match the system used in CILA. Why? Day program is a flat rate yet the CILA program rate varies in relation to an assessed level of need. Why don't people with a high level of need in the CILA have a high level of need in the Day Program? Makes no sense.

5. The ICAP was selected for the ICFIID system in 1988/1989 to meet Medicaid ICFMR requirements. Other assessments have come out since, such as the SIS. HOWEVER, keep in mind that the ICAP and the SIS, and others, were not developed to create a reimbursement system.

   The Day program is responsible for transporting people to and from the Day Program to the residential site. The ICFIID reimbursement system has this requirement because of how FFP was created for Developmental Training services. There is NO waiver requirement that the cost of transportation fall to the Day Program. The ICFIID transportation costs were based on a sample of Day Progam providers in 1988 and there is a specific rate for regular transportation and special transportation (Lift vehicle) in the reimbursement system. The Day program has no identifiable rate for transportation.

6. Professional rates – In the waiver the professional rates are LESS THAN what is paid in regular Medicaid, e.g., for licensed therapist. That makes no sense. It is more difficult to attract

professional to work with people with IDD. The waiver rate should be higher than regular Medicaid to provide an incentive to attract professionals to the field. If that happened perhaps schools would begin to train psychologists, nurses (physicians) etc to work with people with IDD.

7. The IDD waiver is too restricted in the range of supports and types of services for a true community based life style. It's too facility based in concept. A broader array of options should be available, with greater latitude in purchasing the options based on the person centered plan.

8. Employment programs need to be reinvented to be modeled to the consumer rather than a one size fits all system. Work and employment should be the first plan and then modified to other alternatives as necessary.

9. CILA/Day Program surveys – DHS licensing and BQM separately survey. The Licensing standards are "minimum" standards, like IDPH licensing surveys, and BQM surveys providers for State Assurance requirements. The requirements for the two surveys in some instances contradict the other which is an annoyance. However, the biggest issue is that there is no Quality of Life, Quality of Services survey. At some time the waiver system must have push itself to do the best as measured by outcomes based on the person centered plans. Doing the least required does not push the system.

10. We have suggested many changes in Types of Staff and Staffing hour adjustments given increased levels of program services (both medical and behavioral/mental health). If you need additional information, let me know. I think the reports for high need people, sexualized individuals and crisis response in the CILA/Day Program specifies many of these adjustments.

11. A Decision on who can live in CILAs based on (1) severity of IDD (2) severity of medical conditions(s) –an unrelated condition and (3) severity of behavioral health. The Nursing association limits CILA services because only a nurse can do it, e.g., injections, trach care, g-tube use. Changes can be considered based on specialized trained professionals at less than a nurse (DHS, IDPH, HFS whatever certification) to provide a wider range of medical services.) Medical Homes alternatives to NF/SNF placement may provide insight into system changes for IDD programs; or provide an area of overlap under 1115 for home based services for MEDICAL services (no IDD). Again medical is an Unrelated Condition and not specific to a DD Medicaid program.

12. Interdisciplinary process cost annual or special Person Centered Planning. – The CILA system has no specific funding for the professional in the Interdisciplinary team (IDT). The ICFIID system does have a per diem amount of about $668 (based on 1988 costs). Providers have found it difficult to get IDT participation. One option is to create a Waiver rate or to fund it through regular Medicaid somehow. But going to an IDT meeting typically does not fit an ICD- or ICD-10 category.

13. The Waiver has many residential models – 24 hour CILA, Host Family, Home Based and Intermittent to name a few. These models should be reviewed for consistency of requirements, funding concepts and oversight. There should be minimum and best quality requirements if the residential programs gets funding.

14. How does ISSA fit into the 1115 conceptualization? Are the stills PAS requirements, Annual Resident Review (ARR) requirements, in home review etc or will all be intermingled into a new broader system used for all waivers, removing specialization?

15. Transition from DCFS to DHS has been a persistent problem in changing category of Medicaid (child to adult), getting SNAP cards etc. The procedures and responsibilities of each participating department, including HFS should be well defined. The department that errs, not the providers, should incur the cost of improperly managed transitions.

    It can take 3 to 14 months to resolve interdepartmental failures to complete its responsibilities. That means no Medicaid for all medical services AND no CILA payments because the person is not in Medicaid. The 1115 system should resolve all such glitches.

16. Termination of Services – Currently a CILA provider cannot discharge a person from its CILA program. Current CILA rule, 115.215(a) refers to 59 Ill. Adm. Code 120. The CILA discharge is termination of Waiver services!! It cannot and should not be the CILA provider's authority or prerogative to remove someone from the Waiver. DHS has a protection clause by stating that there can be no discharge unless DHS approves it. DHS does not approve discharges. However, that means the CILA provider cannot discharge anyone in its program for any reason to the IDD system.

17. Dying, or over whelming medical conditions. People with IDD now live longer than ever in history.

    We have had people come to the end of their life and stay at home, stay with their CILA family and die in their bed – just like normal people. Hospice services have sometime been used. On other occasions, the person's medical condition is too difficult to allow for residing in the CILA, just like normal people living in their home. There have not been too many issues so far but if a 1115 waiver is implemented such issues should be addressed earlier than later.

Key points: Structuring Medicaid Waivers for Behavioral Support for Individuals Living in the Community

1. Increase the Medicaid rate for psychiatric reimbursement to provide services to dually diagnosed (MI/DD) individuals. This takes into the account the complexity of providing mental health services to those with I/DD, encourages more psychiatrists to specialize in this area and recognizes the chronic nature of treating most major mental illness diagnoses. This rate can be increased under the Medicaid state plan because there is no requirement to demonstrate cost

neutrality under the 2005 Deficit Reduction Act (DRA). (National Health Policy Forum, Background Paper 66: Medicaid and Mental Health Services, October 23, 2008; Shirk, Cynthia, Consultant)

2. Difficulty finding psychiatrists knowledgeable and experienced in working with people with developmental disabilities, including autism spectrum disorders. This is true across the state, but particularly in rural areas of the state. Partner with medical school(s) (i.e., UIC) to provide residency specialization in dual diagnosis and continuing medical education to psychiatrists interested in specializing in dual diagnosis. The enhanced Medicaid rates could be paired with documentation that psychiatrists have met a certain number of continuing medical education units in treating dually diagnosed.

3. Increase Psychotherapy/Counseling reimbursement rate under HCBS waiver for adults. This can be based on reimbursement rate in Rule 132 (attached) for Mental Health providers.
    a. Criteria for qualified providers should be Doctoral or Masters Level mental health clinicians who meet the criteria for **LPHA** and are licensed in the State of Illinois at the clinical level (Clinical Psychologist, Clinical Social Worker, Clinical Professional Counselor)
        i. Licensed Practitioner of the Healing Arts or LPHA − An Illinois licensed health care practitioner who, within the scope of State law, has the ability to independently make a clinical assessment, certify a diagnosis and recommend treatment for persons with a mental illness and who is one of the following: a physician; an advanced practice nurse with psychiatric specialty licensed under the Nurse Practice Act [225 ILCS 65]; a clinical psychologist licensed under the Clinical Psychologist Licensing Act [225 ILCS 15]; a licensed clinical social worker (LCSW) licensed under the Clinical Social Work and Social Work Practice Act [225 ILCS 20]; a licensed clinical professional counselor (LCPC) licensed under the Professional Counselor and Clinical Professional Counselor Licensing Act [225 ILCS 107]; or a licensed marriage and family therapist (LMFT) licensed under the Marriage and Family Therapist Licensing Act [225 ILCS 55] and 68 Ill. Adm. Code 1283. *(Rule 132 Medicaid Community Mental Health Services, section 132.25 Definitions)*
    b. Criteria for qualified providers should be Masters level mental health provider who meets the criteria for **Licensed Clinician** in the State of Illinois, per Rule 132.
        i. Licensed Clinician − An individual who is either a licensed practitioner of the healing arts (LPHA); a licensed social worker (LSW) possessing at least a master's degree in social work and licensed under the Clinical Social Work and Social Work Practice Act [225 ILCS 20] with specialized training in mental health services or with at least two years experience in mental health services; a licensed professional counselor (LPC) possessing at least a master's degree and licensed under the Professional Counselor and Clinical Professional Counselor Licensing Act [225 ILCS 107] with specialized training in mental health services or with at least two years experience in mental health services; a registered nurse (RN) licensed under the Nurse Practice Act [225 ILCS 65] with at least one year of clinical experience in a mental health setting or who possesses a master's degree in psychiatric nursing; or an occupational therapist (OT) licensed under the Illinois Occupational Therapy Practice Act [225 ILCS 75] with at least one year of clinical experience in a mental health setting. *(Rule 132 Medicaid Community Mental Health Services, section 132.25 Definitions)*

4. Increase rates for Behavioral Intervention to previous levels for Level I (Psychologist or BCBA Masters level) at $79.00/hr. Level II BCaBA (Bachelors and Certification) or qualified person with 1500 hours supervision under a BCBA should be reimbursed at the same level as the Licensed Clinician. (see 3b above)

5. Address issue of individual caps on Behavioral Intervention and Treatment services. Current rules cap behavioral intervention at 66 hours/year and Psychotherapy and Counseling at 60 hours/year. This is adequate for most I/DD individuals living in community settings. However, for high risk/high need individuals with dual diagnosis, challenging behaviors and histories of trauma/abuse, there is a need for a higher number of hours/year.

- ***a.*** Possible solution: agency cap rather than an individual cap. This is the way the issue is addressed in the Mental Health system. 100 clients X 60 hours/year or 6,000 hours, for example.
- ***b.*** Possible solution if agency caps are not allowed under DD Waiver guidelines: Tiered system of caps with documentation of high need/high risk individuals receiving a higher cap, i.e., up to 100 hours/year. This could allow for 2 therapy/intervention contacts per week or more frequent contacts initially to assess and train staff, then tapering off as behavior stabilizes.

6. DHS DD develops standard criteria for supervision and sanctions of BCBAs and BCaBAs in accordance with the Behavior Analyst Certification Board rules.
   - **a.** A person who is <u>not</u> certified by the board as a Behavior Analyst (BCBA) or Assistant Behavior Analyst (BCaBA) cannot call themselves a Behavior Analyst. The Behavior Analyst Certification Board's rules are very clear on this and legal action can be taken against these persons.
   - **b.** All Level II BCaBA's (i.e. Bachelor level certified staff)and qualified person with 1500 hours should be required to have supervision by a BCBA at least twice per month.
   - **c.** All persons providing Behavior Intervention services as a BCBA, whether certified or operating under the supervision of a BCBA should be required to adhere to the BACB Rules of Ethics.
   - **d.** According to the Behavior Analyst Certification Board, persons being investigated for poor practice, ethical violations or worse cannot practice and bill for services. They are listed separately on the BACB website as being under sanctions. The state should develop a similar system for listing Behavioral Service providers under investigation and not eligible for services and reimbursement.

7. DHS DD should consider developing additional waiver service descriptions that take into account a person-centered planning model, as has been undertaken in other states. Some examples include: Community Support Teams (Washington, DC), Natural Support Training (Georgia), Community Support Services (Idaho), Family and Caregiver Training Services (Indiana), Supported Community Living (Iowa), Community Specialist Services (Missouri), etc.

8. DHS DD can develop additional waiver service descriptions to address transition and crisis services that result from supporting dually diagnosed individuals and those with challenging behaviors in the community. Some examples include: Other Service Crisis Intervention (Alabama), Behavior Consultation/Crisis Management (Idaho), Intensive Behavioral Intervention (Indiana), All-inclusive enhanced rate (Kentucky), Stabilization (Massachusetts).

9.

Waiver Workgroup Meeting

Thompson Center, Chicago, Illinois

November 1, 2013

Facilitator: Robin Cooper, NASDDDS

Attending: Charlotte Cronin, Parent; Helen Kauffman, Parent ; Jen Knapp, Self-Advocacy Alliance; Shirley Perez, Family Support Network; Sandy Ryan, ICDD;

Phone: Kevin Casey, DDD (introducing the purpose of the group only); Reta Hoskin, DDD; Sheila Romano, ICDD; Michelle Spurlock, Advocate (support staff Katie Fisher); Stephanie Campbell, Advocate (support person Leanne Roth)

Kevin Casey introduced the purpose of the meeting indicating that the group has a "wide open' slate to "push for what you want" in terms of improvements to Illinois' HCBS waivers. He encouraged the group to be creative and set no boundaries, indicating his support for wide-ranging ideas.

The discussion was structured around the following set of questions:

- What supports and services would you want added to the waiver(s)?
- What currently covered waiver supports and services are not working?
- What are the barriers to the services and supports working well?
- What specific changes would improve the waiver program?

Key Themes Emerging from the Discussion:

1. Lack of flexibility in current support options

Service definitions do not allow for flexible options such as using non-disability focused community resources. The day training rate is based on a congregate model, thus it is difficult for day programs to individualize services.

Changes that would improve the waiver: Service definitions should allow for options such as community college, health club memberships and other "generic" community-based, integrated

resources. Resources used for congregate day programs should be available to use for other options (not just in home-based).

2. Supports and services not individualized

Although technically "unbundled" the way CILA is provided results in people getting a "bundled" service. In some instances, if they choose a particular CILA provider there are pressures to choose the day program that particular CILA provider prefers. This is due to transportation issues and coordinating multiple options –it is for the "ease' of the provider but is not individualized.

Changes that would improve the waiver: Individuals in CILA should be advised about and supported to choose multiple options for what they do during the day including employment and other community-based customized supports. Individuals should have access to the funding for day programs and be able to use the funds in individualized, community-based ways

CLIA rates presuppose people are gone during the day five days per week which means people have to out of the home as the home is not staffed. This means that individuals cannot opt to customize their supports and perhaps choose being out the home less than five days a week. Additionally some CILA providers bring individuals from multiple homes congregating people together in another CILA home during the day in order to provide staff coverage.

Changes that would improve the waiver: Assure that the resources available to pay for day programs are flexible and can be used to pay for additional supports at the individuals' home or in customized community options if that is what the person needs/chooses.

CILA is not individualized, and people cannot pick their housemates.

Changes that would improve the waiver: Make CILA more like home-based where you can choose your support. Self-directed CILA is good, but need to clarify what living arrangements will be allowable and supported to occur under self-directed CILA.

3. Employment needs a stronger, more coordinated focus

It was noted that until employment is incentivized, it will not grow. It was noted that many of the very individuals who are easiest to employ work in workshops and keep the workshops financially solvent. Employment is not and expectation and not highlighted as a preferred option. Additionally the requirement of accessing DORS funding first can create serious delays in getting employment supports. One individual reported that although she was eventually "disqualified" by DORS (allowing her to access waiver funding) this process took 8 months.

Changes that would improve the waiver: Incentivize employment for providers and individuals. Make work an expectation and a key conversation in person-centered planning.

Changes that would improve the waiver: Review and streamline process to either get DORS funding or be turned down by DORS.

4. Self-directed services

The group voiced support for self-directed CILA which is in the planning stages now but indicated there are areas needing clarification such as what settings are allowable, who is the employer, and would unused funds be able to "roll-over" to the next month? Concerns were raised regarding the goals of supports brokering and what training brokers will have. With regard to self-directed home-based services, it was noted that outcomes really need to be part of the planning in home-based services. There is some perception that this program has become a vehicle for family income supports and may not be clearly focused on individual outcomes. Questions were also raised about the role of ISSA and the facilitators in home-based services.

Changes that would improve the waiver: More information is needed on self-directed CILA.

Changes that would improve the waiver: Clarify the training requirements and roles and responsibilities of support brokers (service facilitators)

Changes that would improve the waiver: Put more on the individual outcomes of home-based services.